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Complexities in interdisciplinary community engagement projects: some reflections and lessons from an applied drama and theatre project in diabetes care

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ABSTRACT

There is a growing interest in using drama techniques and theatrical performance to disseminate health information to lay audiences as part of community engagement projects. This process can be challenging for a number of reasons, however. In this paper, we describe the process and pitfalls of an interdisciplinary project involving the development and performance of a play about diabetes mellitus. The play formed part of a long-term, three-way community engagement project between social science, applied drama and a diabetes clinic in South Africa. Building on a framework derived from a number of applied drama methods, we elicited narratives from key 'storytellers' that were developed and embodied by actors in a new performance called *Blood Sugars*. Creating this play provided insight into working in an interdisciplinary space and highlighted the importance of establishing shared goals and joint ownership of the project right from the outset. This was without doubt a challenging project and the complexities of finding common ground across three disciplines are not to be underestimated. In this paper, we explore the collaboration and its challenges, drawing on the framework of complexity theory. In particular, we examine the layers of complexity that emerged as a result of the interdisciplinary nature of the project and the demands of balancing the authenticity of the stories with the perceived requirements of health messaging. We consider the methodological, conceptual and ethical challenges of this type of research, and discuss some recommendations for teams taking on similar complex multidisciplinary research and intervention projects.

INTRODUCTION

Globally, a growing number of qualitative health researchers are using drama techniques and theatrical performance both to explore the complexity of health conditions and as a means of educating the public about these health conditions. Community-based education programmes that incorporate drama techniques may increase people's awareness and use of health services (Low 2017; Middelkoop et al. 2006). A WHO synthesis report on the evidence on the role of the arts in improving health and well-being (Fancourt and Finn 2019) suggests that theatre can foster social inclusion, communication around health conditions and reduce stigma associated with health conditions.

Theatre also offers opportunities for communicating research findings beyond the discipline in which they were generated, making research more accessible both in the healthcare setting itself and beyond (Gray et al. 2000; Gray, Sinding, and Fitch 2001; Kontos and Naglie 2006; Sandelowski et al. 2006). Introducing drama into clinical spaces may facilitate greater insight into how healthcare professionals provide care and promote understanding of how patients experience this care. It may increase understanding of the illness experience, improve communication and encourage greater reflexivity in practice (Gray et al. 2003; Gupta and Singh 2011; Kohn 2011; Lorenz, Jillisa Steckart, and Rosenfeld 2004; Rosenbaum, Ferguson, and Herwaldt 2005; Shapiro and Hunt 2003; Singh et al. 2020). Research-based drama may be able to communicate research findings more directly and effectively to stakeholders and, in doing so, holds the potential to change practice as well (Gray et al. 2003).

According to Low (2017), there are two main schools of thought as to how applied drama and other art forms are used in the medical field: 'arts in health' and 'arts for health'. The creative product is the focus of 'arts in health' and any health or educational outcomes are seen as welcome bi-products. 'Arts for health' views art as a means of disseminating information and has health or educational concerns as its primary goal. Those in favour of an 'arts in health' approach argue that creativity of art is in itself, a means of improving our well-being. Matarasso (1997) describes the arts as providing a vehicle for people to examine their experiences, their environment and the relationship between the two and then share these insights with others in a medium that allows intellectual, physical, emotional and spiritual freedom.

'Arts for health' instead advocates that the message contained in the art forms is key. The information disseminated must be accurate, authentic and must protect the privacy of those involved (Norris 2000). Good theatre can disseminate bad health advice and bad theatre negates good information. For example, an overuse of fear tactics, extreme scenarios and archetypal characters can polarise behaviours, undermine the health message and limit discussions (Cahill 2017).

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Participatory or applied theatre cannot be read as a servant to healthcare and health messaging, however. Instead, it is largely underpinned by an activist philosophical framework that 'works overtly either to reassert or to undermine sociopolitical norms' (Prendergast and Saxtong 2009, 8). Augusto Boal's Theatre of the Oppressed, for example, is the root of many of the techniques used in the *Blood Sugars* project described in this paper, and was developed in Brazil in the 1970s as a direct response to political oppression and a capitalism-driven, 'banking' approach to education. Similarly, Theatre in Education developed in the UK in the mid-1960s as a means of challenging educational norms and opening up learners to participation and play. These radical approaches that speak directly to systemic inequality do not necessarily sit comfortably within outcome-based cultures of health and treatment. Moreover, successfully implementing and evaluating a community engagement project is not without its challenges, however, as some authors have reported (Mouw et al. 2016). Working across disciplines may be more difficult than presumed (Rossiter et al. 2008).

This paper reports on a relatively long-term interdisciplinary project that sought to introduce drama and theatre techniques into a clinic space in order to improve communication between patients and healthcare professionals and initiate conversations about diabetes. We discuss the layers of complexity involved in creating a performance that deeply reflected personal experiences while attempting to balance the performance with logistical challenges and the imperative to communicate important health messages. We reflect on the potential of using drama and theatre to educate and inform both the public and healthcare populations, offering some insights and lessons for future researchers and practitioners undertaking interdisciplinary community engagement projects using similar methods.

The condition of diabetes

In the field of non-communicable disease, diabetes mellitus is one of the world's fastest-growing health problems, particularly in low-income to middle-income countries like South Africa. Some experts have estimated that half a billion people around the world currently live with diabetes (International Diabetes Federation. 2017). Yet despite its fast-growing numbers, diabetes has a low public profile in the South African context when compared with other chronic health issues like HIV/AIDS and tuberculosis. A particularly high incidence of diabetes has been noted among urban-dwelling, impoverished South Africans, due, in part to lifestyle factors (Peer et al. 2012).

The majority of people in South Africa living with diabetes have type 2 diabetes. Many of these cases go undiagnosed, however, as initially there are very few symptoms and these develop slowly. Such symptoms include fatigue, excessive thirst and urination, slow wound-healing and skin infections, blurred vision as well as regular bouts of thrush. Lifestyle factors can delay or even prevent a genetic predisposition to diabetes and so the need for public awareness and early intervention is clear (Murphy et al. 2015; Ong et al. 2018; Peer et al. 2012).

Managing diabetes as a chronic lifestyle disease involves a complex mix of education and understanding, lifestyle adjustments, risk factor reduction, optimisation of medical and injectable therapy, and lifelong adherence to these changes. Adherence to medications and the associated counselling regarding education and lifestyle modification are a challenge within the resource-poor, multicultural and multilinguistic society of South Africa. Studies indicate that patients often have a limited understanding of the effects of the disease on the body and of how these can be mitigated by medical management and changes in diet and behaviour (Burkett 2012; Diab 2017; Hjelm, Berntorp, and Apelqvist 2012; Zeh et al. 2012). Moreover, most patients find the required lifestyle changes are difficult to make, and systemic issues and limited care resources exacerbate these challenges (Watermeyer et al. 2020). Poor communication between healthcare professionals and patients can amplify existing barriers to care and obscure the complex relationship between physical treatment and cultural context.

A handful of studies have reported on the application of elements of theatre and drama in diabetes care. For example, Birdsall and James (1999) suggest the usefulness of such approaches in diabetes patient education programmes; Kupper et al. (2018) report that image theatre may be useful for explaining the complexities of lived experience and opening opportunities for changing adherence behaviours; Popelier et al. (2019) found that a 'living theatre' approach grounded in narrative medicine produced positive effects on illness perceptions about diabetes and Kananzoe (2016) suggests that the popular theatre process provides a viable health education methodology for diabetes care in a developing context. Further research is required, however, to understand the lived experience of people living with chronic illnesses as well as how applied drama techniques might empower people living with diabetes and drive personal change (Kupper et al. 2018).

Background to the project

In response to some of these challenges, and with the aim of creating a healthier, more nuanced and better-informed dialogue around physiology, treatments and the cultural context of diabetes care, the *Blood Sugars* project was born. This was a 3-year interdisciplinary research, clinical and drama collaboration in South Africa. The funders for this project specified that the emphasis should be on community and public engagement as well as on knowledge translation and communication to wider audiences. The project had a number of phases, including preparatory research, drama workshops at the clinic and the sharing of stories, culminating in the development and performance of a play that dramatised the stories of people living with diabetes, and of the healthcare professionals working with them. A theatrical production seemed a good fit given the strong oral tradition in many African contexts, whereby stories are used to deliver important messages (Middelkoop et al. 2006).

Multiple processes and objects were involved in this project. These included not only the collaborators but also the participants and the South African healthcare context. The project was characterised by a number of challenges and tensions, some of which have become clear only in hindsight.

In analysing the process and outcomes of this project through an evaluation process, we used a lens of complexity theory to examine the dynamic, intertwined variables at play. Complexity has been described as 'a dynamic and constantly emerging set of processes and objects that not only interact with each other, but come to be defined by those interactions' (Cohn et al. 2013, 42). Both systems and interventions are complex by nature, often with 'fuzzy boundaries' and characterised by unpredictability (Greenhalgh and Papoutsi 2018). In many instances, interventions are applied to particular systems such as healthcare contexts in a compartmentalised way that tries to break down the messiness of everyday practice into individual components (Reed et al. 2018). Instead, the reality is that interventions themselves are not detached or distinct events, but rather they involve complex processes, sometimes the blurring of professional boundaries,

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and are introduced into contexts and systems that are themselves complex. Complexity theory does not strive to create solutions, but instead offers opportunities for understanding complexities in an intervention and/or system as well as how the components of these complexities and the agents' actions in the system influence each other (Gatrell 2005; Greenhalgh and Papoutsi 2018; Thompson et al. 2016).

THE PHASES AND METHODS OF THE PROJECT

Research design

The project involved collaboration between the University of the Witwatersrand's Health Communication Research Unit (HCRU), Drama for Life (DfL) (an academic community engagement department) and the diabetes and endocrinology clinic at Chris Hani Baragwanath Academic Hospital in Soweto (known as Bara). The project was initiated by the HCRU, who over the past 15 years have conducted long-term educational and research work, which focuses on understanding barriers and facilitators to care (Penn and Watermeyer 2018). DfL is a specialist postgraduate centre focused on applied drama and drama therapy. It provides the only postgraduate drama therapy courses in South Africa. It sits at the intersection of the non-governmental organisation and university worlds, often bringing the two together in various service learning or applied contexts. The HCRU and DfL have a history of collaboration dating back many years (specifically in the field of HIV/AIDS), although this was the most substantial and sustained collaborative project attempted. The HCRU had also previously conducted research at the gestational diabetes clinic at Bara. Our aim from the outset was for social scientists, creative practitioners and healthcare professionals to work in close collaboration throughout the project.

We adopted a 'slow' research approach to this project, focusing on a prolonged relationship with the site, multiple site visits and in-depth research with participants (Adams, Burke, and Whitmarsh 2014). Following a period of preparatory research in the clinic, we held a series of drama workshops, also at the clinic, with patients and healthcare professionals. Key participants then worked closely with a team of actor-devisers to develop a play based on their experiences, which was performed in a variety of settings. The drama content was framed and informed by academic study and the results of our interventions were documented to consolidate and guide further research in the diabetic field.

Participants were invited to participate, the study was explained to them in the language of their choice and they signed written consent.

Patient and public involvement

Although patients and the public were involved as participants in the research, they were not involved in the design, or conduct, or reporting, or dissemination plans of the research.

Project site

Chris Hani Baragwanath Academic Hospital is the largest hospital in the southern hemisphere and the third largest in the world. Soweto is linguistically and culturally diverse and home to 1.5 million people. The area faces high levels of unemployment and poverty. Six thousand people are managed at the diabetes clinic at Bara every year, which hosts one of the few specialist diabetes education centres in the region.

Overview of project phases

The project involved a number of phases, outlined in figure 1.

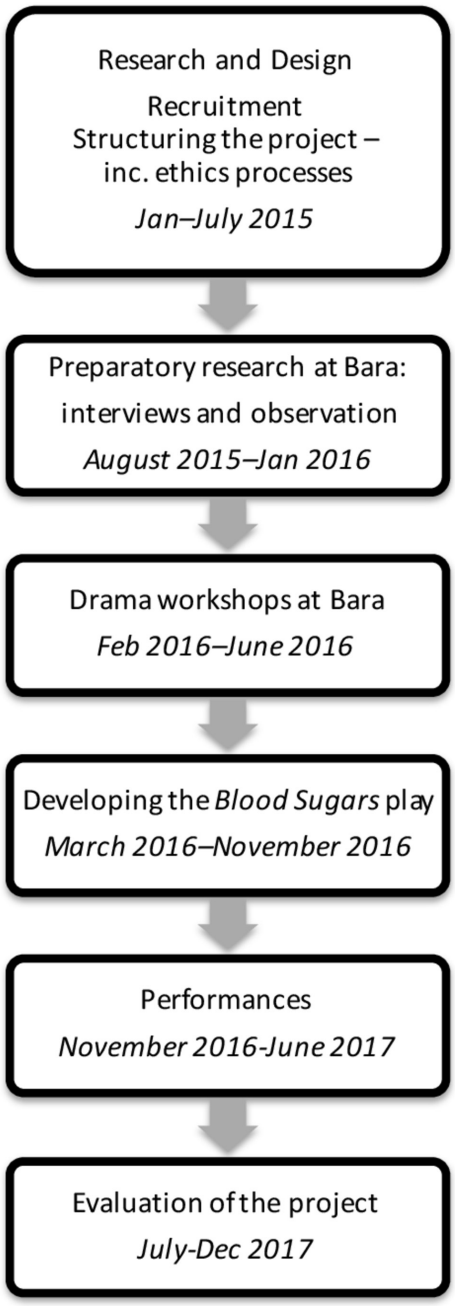

Figure 1 Phases of the project.

The project began with a series of meetings to flesh out the activities described in the original funding application. These included team meetings for key members and a research day at DfL, at which an expert physician discussed the physiology and psychosocial challenges of diabetes. The team then held an initial meeting with the clinical team at (Bara) to discuss implementing the plan described in our initial application.

Preparatory research

It was decided early on that we would need to use qualitative research techniques to help develop the community engagement activities—that is, to understand where the communication gaps lay in the clinic in order to lay the foundation for developing an intervention that was attuned to identified challenges. Research was devised as a series of four phases under the title 'What are the barriers and facilitators to care experienced by people living

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with types 1 and 2 diabetes and healthcare professionals in Soweto and Johannesburg?'.

Two research assistants—an applied drama specialist and a psychology graduate based at the HCRU—worked together to conduct a period of preparatory research at the diabetes clinic at Bara. This research comprised ethnographic observations, interviews and focus groups with people living with diabetes as well as with healthcare professionals (methods and results from this preparatory research phase are described in detail elsewhere—Penn and Watermeyer 2018; Watermeyer et al. 2020).

The assistants' first tasks were to observe the space and how it functioned and to act as champions for the project, explaining our aims to clinical staff and opening the door for the drama workshops to come. After a period of observation, they moved into conducting interviews with 38 healthcare professionals and patients to establish the framework for drama workshops. Data were transcribed, translated and examined using thematic analysis (Braun et al. 2019). The Standards for Reporting Qualitative Research checklist was followed for this phase of the project.

The findings from this preparatory research indicated that facilitators of care revolved around relationships and support from family and healthcare professionals. For the healthcare professionals, care was facilitated by teamwork, job satisfaction, peer support and rapport. For the patients, care was facilitated by acceptance, family support and service satisfaction at the health facility. Healthcare professionals identified the barriers to care as patient loads, resource limitations and structural issues. Patients reported barriers to be psychosocial factors such as poverty, lack of understanding of the physiology of diabetes and the complexity of disease management. The analysis highlighted communication between all stakeholders as a key component of diabetic care.

Drama workshops

In parallel with this work, DfL engaged a group of actor-devisers to develop and perform a new play. They were all drama graduates, some of whom had experience in community-based projects. This team was given a week's intensive training in applied drama techniques and employed on a regular basis as the *Blood Sugars* company.

Having got a broad sense of how the clinic worked, six applied drama workshops were conducted in the clinic, separately, with people living with types 1 and 2 diabetes and with healthcare professionals including doctors and nurses. The workshops, facilitated by a qualified drama therapist working with the *Blood Sugars* company, aimed to create a healthier dialogue and improved communication between patients and healthcare professionals, by providing opportunities for reflection, engagement and discussion around the contextual and daily challenges of living with, and treating types 1 and 2 diabetes. These workshops were carefully planned and structured, and involved applied drama techniques including playback and forum theatre. The *Blood Sugars* company also held separate meetings with doctors working in the clinic who were unable to attend larger workshops, observed the clinic space to support the later development of the play, and took part in debriefing and reflective practice sessions facilitated by the drama therapist.

Developing the *Blood Sugars* play

The project team felt it was important to develop a play in which the voices of those living with the condition were authentically embodied through actors, raising awareness not just of the causes of diabetes but also its treatments. This storytelling aspect of the project was informed by an approach used in *Through Positive Eyes* (TPE),[1] a collaborative photo-storytelling project in which DfL had previously been partners. The TPE project provided a short-term, therapeutic experience for HIV-positive individuals to learn photographic skills and engage with their own lives through the lens of a camera, ultimately producing self-portraits fused with their own narrative prose. We extended this approach to asking people living with diabetes to share their life stories.

The original plan was to locate a representative group of key 'storytellers' during the drama workshops—ideally a range of individuals including patients with types 1 and 2 diabetes, a nurse, a doctor, family members and dietitian for a truly rounded performance. Four storytellers were ultimately recruited—three patients and one healthcare professional. The patient storytellers were each paired with an actor-deviser and worked closely with them over a day-long workshop. The healthcare professional was interviewed separately at (hospital name) by an actor-deviser.

These 'small stories' (a term coined by Georgakopoulou 2007) were blended into a larger performance of about 45 min, co-directed by the drama therapist and one of the actor-devisers. The performance comprised a number of vignettes portraying the unique narratives of different individuals and some of the main challenges of prevention, diagnosis and living with the diabetic condition in a South African context. Storytellers were given the opportunity to watch and comment on *Blood Sugars* before its first public performance. Two of the three patients attended a dress rehearsal and provided feedback; the healthcare professional fed back on the basis of a first performance at Bara itself. This feedback was all incorporated into later public performances.

Performances

Blood Sugars was presented in a variety of settings in Gauteng province—including two theatres, a children's home, a youth group, a conference, at the hospital itself and at a support group for diabetes. It was presented at the launch of the *Lancet Commission on Adolescent Health and Wellbeing* in Johannesburg and was also chosen as a keynote performance at the *Culture, Health & Wellbeing International Conference* in Bristol, UK, in June 2017.

The play was developed iteratively across the performances. Each performance was followed by a discussion at the venue, facilitated by the drama therapist/co-director. A diabetes nurse educator was present during these discussions to support the team with clinical expertise. The audience was encouraged to ask questions and talk about their own experiences. The research team used ethnographic techniques to record the audience's responses to specific aspects of the performance, and to the discussion. Based on these additional data sources, each presentation led to tweaks in the content and narrative, including the correction of some clinical inaccuracies. Some performances were documented with film and photography.[2]

Much of the storytelling material was collected in vernacular languages, by researchers and actors conversant in the first languages of the participants. The performance that emerged was multilingual, and its code-switching reflected the true nature of narratives in this country, particularly in healthcare. A decision was made to preserve the vernacular elements even for the British performance—something which appeared to have a positive impact and which aligned with transformation imperatives.

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Evaluation

After completion of the project, we evaluated the collaboration between the three entities using a lens of complexity theory. Our evaluation was based on data collected via several sources, including:

1. Minutes from formal project team meetings and notes from frequent discussions among project managers.
2. A semistructured interview with one storyteller after the process of creating the play was complete.
3. Storytellers' responses to a dress rehearsal.
4. Performance evaluations undertaken by a number of staff at the HCRU.
5. Vox pops from audience members, recorded after performances of the play.
6. Workshop leaders' reflective notes.
7. Evaluation discussions with project managers, co-directors and actor-devisers led by the project coordinator.
8. Evaluation discussion with a senior consultant at Bara's diabetes endocrinology clinic led by the project coordinator and one of the researchers.
9. Social media interactions.
10. Responses to presentations of the work at conferences.

These sources were collated and analysed using principles of thematic analysis (Braun et al. 2019). Several team members were involved in this process, including the principal investigator, project manager and one of the research assistants.

REFLECTIONS ON CHALLENGES AND PITFALLS IN THE PROJECT: SOME TENSIONS AND LESSONS

Unsurprisingly, this collaborative project had challenges, particularly around competing orientations and goals. We were met with multiple internal and external challenges—from clashing expectations, to complex payment systems for freelancers, to massive logistical pressures at Bara, to the emotional and logistical impact of concurrent student protests on campus. Although we met our objectives, and individual elements worked well, many key team members shared a sense that more could have been achieved. In this section, we reflect on a number of challenges identified during and after the life of this project. These include interdisciplinary issues, the maintenance of aesthetic as well as research integrity, logistical issues and the question of how to measure the impact of the intervention.

Interdisciplinary issues

The project involved a three-way collaboration between social science, the arts and clinical practice. Though our aims were the same, each collaborative partner clearly came from a very different disciplinary world, with different cultures, approaches and agendas. Disciplinary tensions manifested not just in the complexity of the healthcare system—the context for our research— but also in the collaboration between three very different groups. Tensions also arose from the contrasting expertise of each partner, a lack of stability and continuity in terms of the people involved (and at times too many people involved in the project), expectations and assumptions, power and hierarchies between collaborators, and a lack of flexibility. These all impacted on the project and were sometimes identifiable and resolvable, but in other instances were both intractable and only fully visible in hindsight. Table 1 summarises some of the benefits and challenges of our partnership.

Through our evaluation, it became clear that stresses on one relationship in a tripartite partnership will inevitably impact the other relationships. While our broad overall aim was essentially the same (ie, to improve communication around diabetes), the specific goals for each collaborative partner emerged as being quite different, and the complexity of achieving these goals was underestimated in an assumption that collaborators would 'gel' because we were essentially 'on the same side'. For example, it was only during our evaluation that it emerged that what the doctors really wanted to get out of this project was a drama therapist to work in their clinic, and they saw the development of the play and the plan to create a film as an HCRU/DfL project rather than something with which they were explicitly involved as equal project partners.

Social science and applied arts are both based in the humanities; one might expect them to be more natural partners than biomedicine. Perhaps because of our assumption of similarity, we underestimated the paradigmatic difference between the two and the friction this might cause. One actor-deviser clearly identified the real culture clash as being between the social sciences and drama, not between the humanities and medicine. He felt that the hospital simply presented a structure within which the *Blood Sugars* company had to work, whereas the relationship between the social sciences and applied drama was hampered by the problems of (disciplinary) language and culture and burdened by the HCRU's expectations of how drama worked and what it could achieve.

The lack of shared vision between the project partners created a periodically oppositional relationship. It is possible to trace the challenges back to the original funding application which, as often happens, overpromised outcomes to provide a compelling case for funding. The combination of detail required in bids and lack of time teams can devote to planning an as yet unfunded project compromises the relationship building needed for a sustainable project plan. The social science team, driving the project, became at times the disciplinarian voice of the funder, conscious of promised outcomes. A lack of nuance in the other partners' perceptions of each other's disciplines—an inevitable part of cross-disciplinary programmes—meant that social science techniques were conflated with this role and at certain crunch-points perceived as both opaque and reductive in relation to the TPE methodology.

The project was conceptualised by the heads of the HCRU and DfL, who had a particular vision for how the project might work and how the disciplines would come together. However, they were not the people on the ground implementing the project and attempting to realise this vision. As a result of this disjointedness, the actor-devisers and the directors reported lacking a strong sense of the overall vision for the project and

Table 1 Benefits and challenges identified in the three-way collaboration

	Benefits	Challenges
Social science *HCRU*	► Research structure ► Access to hospital partnership ► Formal ethical support ► Research outcomes	► Mediating role ► Sustaining research momentum ► Limited understanding of dramatic processes
Applied arts *DfL*	► Greater access to more complex information ► Peer support ► Greater public reach ► Non-didactic; conversational	► Sustaining creative momentum ► Flexing to accommodate the circumstances of the hospital and the limitations of ethical clearance ► Achieving balance between performance aspects and health education aspects
Medicine *Bara*	► Clinic work enabled greater understanding of clinical as well as patient's perspectives ► Openminded approach to multidisciplinary support	► Initial suspicion and misunderstanding of both applied arts and qualitative methods ► Resource/time pressures

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felt that they needed constant reminding of the point of the project throughout the 3-year process.

Although a 'slow research' approach was adopted for this project, it seemed that the social scientists had not fully appreciated the significant process involved in turning patient narratives into a play. The applied arts team members felt pressurised to produce a tight, neat script, which was not a natural product of this particular drama process. One of the directors reflected that they found it difficult to articulate to the HCRU head that the drama aspect 'is not going to work like that' and they did not feel empowered to take initiative during the course of the project for fear of 'getting things wrong'. The power imbalances and disconnect between the project heads and the team on the ground resulted in frustrations on both sides and ultimately affected the momentum of the project.

Although the social science and applied arts heads met with the directors and project coordinator at several intervals during the life of the project, these meetings were usually not held with the entire applied arts team but rather with the directors and/or coordinators, and they generally did not include the medical team. There were thus few opportunities for the actor-devisers to voice concerns or talk through challenges with the heads, and also few opportunities for the medical team to give regular input during the project. When the heads did provide input, this was sometimes fragmented or did not adequately address the challenges on the ground. For example, at one team meeting, the HCRU head mentioned an idea to create branded t-shirts for the applied arts team to promote a sense of team building. Although a good idea in theory, ultimately it proved a distraction that resulted in time wasted on logos and design.

The social sciences offered a research structure around the whole project. This provided the background knowledge we needed to start the drama workshops and also gave us a way into the clinic, thanks to previous research conducted by the HCRU in the same hospital. Social scientists were the principal investigators for this project, yet (after the initial period of research and development) the applied artists took on much of the practical work of engaging with participants and the clinic site, and developing and performing the play. Some of the actor-devisers perceived a lack of a clear, consistent vision between the two approaches. For example, during workshops and focus groups, the applied arts team wanted to probe further with patient participants and really 'get into' the emotional aspects of living with diabetes in a much deeper way. However, they felt hampered by the agreements set out in the ethics applications (compiled by the social science team), which did not allow for such detailed emotional exploration. Ultimately, the resources required to make the relationship between social science and applied drama work meant that too little time was given to the relationship with the third partner, Bara, which was both physically further away, and working with methodologies more distant from those of the two humanities partners.

Initially, there was a level of suspicion and misunderstanding of both applied arts and qualitative methods from some of the healthcare professionals at the clinic, related in part to concerns over 'helicopter' research in their clinic space that would not be sustainable without on-going funding. In general, however, our clinical partners demonstrated great openness to intervention from outside disciplines. Resource pressures at the hospital affected the project in negative ways, making it hard to organise time and space to work with clinical staff in particular and to include the medical team in project meetings, but they also created openness among the clinicians who were actively looking for support outside of conventional health models. A further advantage of working in this space, as opposed to, say, a community setting, was the access it gave us to the full picture of healthcare systems, rather than the patient's perspective in isolation. Understanding the pressures on nursing staff, for example, is as vital to improving diabetes care as learning about food security in patients with diabetes.

Balancing aesthetic and research integrity

At the heart of this project was the *Blood Sugars* performance—it was the point to which all to roads led, and intended to be the sum of all our research, from which would then spread the 'broader dissemination', including a training package and papers such as this one. Moreover, it was the use of applied drama that moved us from superficial data to something far richer and more revealing, that provided a depth and richness to our understanding of diabetes care. Techniques like Forum and Playback theatre allowed doctors, nurses and patients to inhabit a more intimate emotional space, and developed a trust that led to sharing richer detail about their various experiences. The approach gave us a more detailed sense of the challenges confronting them, and how these might impact on communication. The drama workshops also created a sorely needed space for peer support among three different groups: patients, nurses and doctors. Indeed one of the limitations of the project was our inability to embed this peer support in the clinical space in the longer term.

During the process of creating the play, however, we ran into a major obstacle. In the minds of those in the HCRU, we had several sources of information for this play: general research into diabetes, the initial research (interviews, observation, focus group), the *Blood Sugars* company's time in the hospital and the storytellers. To the HCRU, these were all compatible—if different—sources of information. This was not the case for the co-directors and actor-devisers, however, who felt the power of the play would come from the stories shared by the key storytellers. The process of learning these stories, relying on the relationship between actor-deviser and storyteller, was quite different from, say, reading a transcript of an interview, and the actor-devisers were reluctant to dilute the creative process. For example, while the HCRU focused on conducting interviews across different groups of participants to get a sense of cross-cutting themes, the actors were satisfied with the depth of information they had obtained from just one or two storytellers. During the evaluation, the directors asserted that the research aspect was too strongly foregrounded in the project. The applied arts team felt under pressure to incorporate elements of the social science research into the play and felt they had let the HCRU head down by not managing to incorporate the bigger picture of the research findings into the play. This is not to say that drama cannot be made from interviews—far from it. But from the actor-devisers' perspective, this project had been conceived around a different process, one grounded in processes successfully used for the TPE project.

A second source of conflict was around what might be called public health messaging. One of the social scientists' goals (working to an action research model) was to produce a performance that would give out accurate information about diabetes, dispel existing myths, differentiate between types 1 and 2 diabetes and discuss key concepts such as prevention, early diagnosis, adherence and lifestyle changes. Equally, the diabetes educators and physicians at Bara felt that health education should be a key aim of the play.

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The actors' narratives instead concerned the broader stories of people's lives. The emphasis was on establishing the characters' dreams, aspirations and key relationships before exploring the impact of the condition. The narratives that emerged from the storytelling phase of the project highlighted the enormity and breadth of the challenges of the disease in context, from the resource pressures affecting government health providers, to a lack of public understanding of the condition, to complex treatment regimens that impact every area of life, from food to employment to relationships. Their stories were just that, the narrative of their lives, with how they navigated universal experiences such as blossoming love, a loved one's death, even emigration. Diabetes is of course only one aspect of people's lives and would therefore drift in and out of the focus of the storytellers' narratives. In the first performance at Bara, diabetes was mentioned for the first time 30 min into the 60 min production.

The clinicians' response was initially to challenge this breadth. A doctor attending the first performance turned to his colleague and asked, 'Isn't this supposed to be about diabetes?' and when the HCRU team was given an opportunity to observe the play, a large proportion of the comments focused on correcting clinical details rather than on the overall impact of the performance. The detail of disease management and the research findings were the researchers' main concerns. Since neither the actor-devisers nor the storytellers were medically trained, some of the stories risked reinforcing misconceptions around diabetes.

For the actor-devisers, however, the priority was to honour the storytellers' words and produce a powerful performance. They felt at times that the changes the social scientists and clinicians required represented an invasion of the rehearsal process. The time-consuming process of negotiating this conflict suggests in retrospect that far more energy and time should have been given to developing an agreed vision, as well as trust and respect for each other's roles and responsibilities in this tripartite relationship.

A compromise was eventually reached through an iterative process of tweaking the play each time it was performed, and it required skilful crafting on the co-directors' part to weave key clinical information into the stories. The TPE approach was indicated by the storytellers themselves, who commented at the dress rehearsal that the *Blood Sugars* company had 'got them' and that it was a powerful, healing experience to 'see' *their* stories on stage.

The performance ultimately emphasised the fact that these were first and foremost people, who just happened to have the additional burden of living with diabetes. When it came to the actual performances, we were amazed by how quickly and comprehensively audiences engaged with the topic; it was very apparent that audiences were hungry for this information. But it was the absence of didacticism that challenged the stigma around chronic disease, and created a space for people to ask these questions and indeed to question the stories. The drama allowed us to recognise our own lives in these stories, rather than be distanced by a predetermined public health model. The dramatic process, too, brought with it support and debrief structures of a more informal kind, but absolutely crucial to the democratising approach of the project and the capacity to create spaces (both in the hospital and at performances) that challenged pre-existing hierarchies in the clinic space.

Theatre in relation to health presents multiple possibilities. Approaches like Forum Theatre, Playback and the TPE framework have been developed within specific social and philosophical frameworks, and may or may not be applied to create predictable outcomes. The kind of empathic storytelling elicited by TPE, which underpinned the *Blood Sugars* play, cannot necessarily be used efficiently to carry specifics of public health messaging, but may facilitate audience empathy and reduce stigma towards a particular disease (Gere 2011). The Forum Theatre/Playback technique used in the hospital-based workshops does an entirely different job of eliciting and valuing life experiences, and building the confidence of participants in their own agency to create stories. These techniques do not work additively, however. They are rooted in different approaches and depend on different power relations between participant, audience and 'professional'.

Moreover, the idea of health messaging on the basis that knowledge can be passed down from an educator as a truth to the learner (public audience or patient) is philosophically antithetical to much of applied drama, which exists to overturn social hierarchies and question or recontextualise such truths. This may have led to an ethical discomfort for the actor-devisers, which manifested in the sense of rehearsals being invaded and a defensive position in relation to the social science partners. In the meantime, feeling pressure from both clinical partners and the ghostly funder in the face of a lack of reference to diabetes in a project about diabetes, the social science team retreated to a place of safety, namely the didactic health messaging that sits so awkwardly with the TPE approach.

Project management challenges

Logistical issues abounded, from financial management and travel and transport issues, to complex scheduling and 'fuzzy' roles.

Fuzzy roles: All the key players' roles expanded beyond their official 'job descriptions'. The scope of this multidisciplinary project demanded significant flexibility in roles. Researchers became administrators, drama therapists became directors, applied drama facilitators became (social science) researchers and so on. This came with the pros of personal and professional development and the cons of exhaustion generated by switching between creative, research and administrative work. Getting freelancers admitted into the relatively inflexible systems of the University also created challenges around contracting and invoicing.

Travel and transport: Johannesburg has limited public transport infrastructure and there are significant dangers attendant to travel after dark or very early in the morning. These factors impacted on travel to and from the hospital, rehearsals, meeting storytellers and travel to performances—increasing costs and administrative load significantly.

Time and timetabling: It was a challenge to find both storytellers and freelance actors who were willing and able to commit to this relatively lengthy project. From the storytellers' side, our budget allowed us to provide only a very small stipend and compensate for travel costs. The work of developing and then evaluating the performance was happening in Braamfontein, a district some distance from the hospital in Soweto, and from their own homes. For the actors, who were very experienced in fast, responsive work over short, intense projects, to stretch the creative process across more than a year represented a huge change in approach. This project took almost 3 years to complete; for both storytellers and the *Blood Sugars* company, other work commitments and personal priorities inevitably competed. The actor-devisers were too much a part of the play's evolution to be replaceable, so when the lifeworld intervened and they were unavailable for rehearsal and performances, the show could not go on.

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The difficulties of working across hospital, university and freelance timetables also limited our work significantly. During the initial research phase, the research assistants managed to spend 1–2 days a week in the clinic. Once the workshops began, however, the combination of pressured hospital time, clashing university timetables, and a team of freelancers that was perhaps too large to be collectively flexible meant that the team was not at Bara as often as we would have wished. One actor-deviser expressed concern that because they were limited to visiting the hospital on specific days, they may have missed out on opportunities to hear the full range of people's stories.

Ethics applications: The project required four full ethics applications to the University's Institutional Review Board. This was a hugely time-consuming process because of the relatively unusual nature of the data-gathering and dissemination processes. The approvals ultimately provided freedom to perform people's stories, to use data in public settings, to document the project and to create long-lasting, publishable outputs. Sustaining momentum despite the delays caused by multiple ethics applications was a significant challenge, however.

External challenges: The peak of the #FeesMustFall movement[3] occurred just as the late 2016 performances began. Protests shut the university down for much of the rehearsal period, which meant moving rehearsals to a nearby theatre in Johannesburg. We were also forced to cancel plans to perform at the university's health sciences campus, and at the university's theatre. #FeesMustFall also added considerable pressure to the workloads of the team: the exam period was extended beyond the normal end of term, and the demands of pastoral care increased substantially, particularly for DfL, who were heavily involved in creating 'safe spaces' for students on campus during periods of significant violence on and off campus.

Measuring impact

As is frequently the case in projects combining arts interventions with clinical care, the question of how to measure impact becomes paramount. What should we measure—attitudes, behavioural change, self-efficacy dimensions, reduction of stigma, empathic enjoyment, authenticity, accuracy of knowledge pre and post performance and so on? How do we know if what we have done has been effective, not only for those who have participated in the project but also for the future management of diabetes?

These questions remain a particularly prickly problem in the field and a strong call has been made to include contextual and qualitative material as evidence (Campbell et al. 2000; Lambert 2013). While researchers have long believed that arts interventions are effective in altering attitudes, the multivalent nature of arts interventions, the lack of solid methodologies and objective outcome measures, and the largely anti-instrumental philosophical imperatives of the applied and participatory arts have made it difficult to judge these claims. There are very few studies that measure the effects of such interventions on behaviour (Perry et al. 2011), other than some relating to interventions with children (see Mora et al. 2015; Quek et al. 2012). Much of the research on dramatic performances has been geared to helping practitioners and medical trainees reflect on the care they provide and increase their understanding of patient care issues (Gray et al. 2003; Lorenz, Jillisa Steckart, and Rosenfeld 2004; Rosenbaum, Ferguson, and Herwaldt 2005; Shapiro and Hunt 2003).

Several authors point to the particular challenges of measuring complex interventions that involve drama and theatre techniques (Moore et al. 2014; Pagani et al. 2017). Gesser-Edelsburg, Guttman, and Israelashvili (2006) caution that although the use of drama techniques can produce 'learning through enjoyment', enjoyment may not actually translate into meaningful behavioural changes, leading to a 'false catharsis'. Reed et al. (2018) suggest that everyday practice is often messy and complex, and if tidied into discreet intervention or evaluation components, the complex reality of an intervention in a particular context may be missed. Using a complexity theory approach, they suggest it is more important to consider the context and ask 'what works, for whom, in what settings?'.

Despite the difficulties we have outlined above, there is no doubt that the play was profoundly engaging and started much-needed conversations about diabetes. All the core team members and the *Blood Sugars* company perceived the project as a success in terms of public engagement, moving from the private space of the hospital interviews through the workshops and into performance in a series of public spaces. The impact on patients and healthcare professionals during the preparatory research stage was also clear. There was a willingness to share information and an obvious pleasure in being asked about their experiences, especially in their home languages. The storytellers, in particular, highlighted the cathartic value of being able to share their stories and experiences with an audience through the play. Audience responses indicated that as entertainment and a tool for providing insight into the lives of those living with diabetes, the play was a resounding success.

The long-term impact on the clinic as a whole is difficult to judge, particularly since the challenges we describe above severely limited the number of drama interventions we could bring to the clinic. The project managers were all convinced of the impact on patients attending workshops, but less sure that we had any impact on the 'system' of the hospital in particular. This was borne out by a senior consultant at Bara, who confirmed that the impact on the clinic's systems had likely been quite limited and that the project would have required more sustained efforts to extend its reach. Effectively this meant that one initial aim, of improving communication between groups at the clinic (clinicians and patients), had lost ground to communicating the realities of diabetes to a more dispersed, public group.

The impact on the actor-devisers was easier to track. The reflective practice in which they were engaged throughout the project revealed that they felt enriched by the experience of interdisciplinary work, and that they had developed great insight into the lived experience of diabetes in their community. Unexpectedly, we discovered that almost every creative and administrative professional involved with the project had *at least* one member of the family living with diabetes. Several team members noted significant impacts on their family's understanding of diabetes and capacity to discuss it openly as a direct result of their involvement in this project.

CONCLUSIONS

The combination of the applied arts and social sciences in this project gave access to rich, multifaceted, personal data, which represented the complexities of health and treatment for *both* patients and healthcare professionals. It started a much-needed conversation about diabetes and hinted at the huge potential of such partnerships for projects with complex conditions. The introduction of drama into a clinic space enabled people to connect, engage and see new things, and for the storytellers it facilitated what Mitchell et al. (2011) refer to as an 'unburdening' in telling their truth.

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The complexities of collaboration across three disciplines are not to be underestimated, however. Several authors have written about interdisciplinary tensions in projects of this nature (Broderick 2015; Pauluth-Penner 2010). There will always be tensions about aesthetics and knowledge accuracy (Cox 2014): actor-devisers want to acknowledge the complexity of their participants' lives as well as the disease, and it is challenging for scientists and actors to interact in terms of how and what information is to be shared. Added to this tension is the inevitable lack of infrastructure, time and skills to support such projects, rendering most endeavours unsustainable and under-researched (Jennings and Baldwin 2010).

As Gray and Kontos (2019) remind us, however, such collaborative opportunities offer potential for challenging assumed understandings and they open spaces for new possibilities. The end product may not have been what the HCRU had envisaged in that the educational aspects of diagnosis and treatment made way for the life experiences of the storytellers. There were challenges in evaluating its impact. However, the process itself gave depth and meaning to the tapestry of what it means to live with diabetes and was in its creation, educational and empowering for all who participated.

One of the key learning points from this project experience is that the development of a performance using the TPE approach affirmed the identity of all its participants and provided new insights into the relationship between the health condition and a wider life experience. The use of different drama games and approaches based on Forum and Playback Theatre in a clinical setting also proved effective in terms of eliciting complex, emotional stories of health and illness (see Watermeyer et al. 2020).

The play succeeded in presenting the experiences of both patients and healthcare providers; achieving what Mishler (1984) described as bridging the voice of the lifeworld with the voice of medicine, and what Mitchell et al. (2011) described as dissolving disciplinary and doctor–patient silos among the audience. This was evident in the audience reaction, the impact on the actors themselves, and the affirmation from the storytellers, doctors and nurses that their stories had been honoured. It stimulated significant new conversations about diabetes. The creative process encouraged intergenerational and interdisciplinary communication and a blurring of the disciplinary boundaries. The development and performance of the play contributed significantly to the professional development of the project team.

We believe that this project presents an approach to health education and health communication that has significant potential, and one that could be transferred into other health contexts. But it is a work in progress and needs refinement if the model is to prove effective in intervention spaces.

Based on our experiences and evaluation of this project, we offer the following thoughts to teams undertaking similar work:

- *Build partnerships*: Nothing should be taken for granted in work across disciplines. To create sustainable innovative practice, a project's resources must initially be invested primarily in the core partnerships. Assumptions are dangerous and collaborative projects need to build in mechanisms to facilitate trust building and open discussions about how to navigate logistical as well as interdisciplinary challenges. Significant time should be given to developing clear, agreed upon, shared goals that can be revisited throughout the project to guide processes; to discussing the particular methods and approaches used by each discipline and to establishing the priorities, roles and responsibilities of all the players early on. This process should begin before funding applications are completed, to ensure outcomes fit each partner's purpose and philosophical approach. Moreover, any methodologies (creative or academic) foreign to one part of the partnership should ideally be tested within the partnership before being used with participants. Without this clarity, there will be a lack of direction, misunderstandings, delays and mistrust.
- *Do less*: We included two broadly contrasting methodologies (one inward-facing—hospital workshops and preparatory research (Forum/Playback) and one outward-facing—performances (TPE)), and ticking both these boxes may have left us unable fully to explore the potential of either. To negotiate the beliefs and practices of each discipline required more resources and time than predicted. It also required us to lower our expectations from those set out in our original grant application. On reflection, several team members suggested that it might have been more useful simply to focus on introducing drama workshops to the clinic, rather than extending the project into developing a play.
- *Flexibility:* The flexibility required to make a long-term collaborative interdisciplinary project work was significant. We would suggest reviewing project goals on a regular basis with an open mind to radically adapting key elements (preferably in conversation with the funder).
- *Keep the core team small and communication strong*: Our collaborative team was comprehensive, but often too unwieldy for everyone to attend regular meetings, resulting in miscommunication and slowed processes. We suggest then that a core team is formed, representing each of the collaborating disciplines, with a focus on regular meetings and strong communication.
- *Ring-fence funding for external evaluation*: The challenges of assessing the impact of a multimodal intervention such as applied drama on communication and knowledge around chronic disease are significant. An external evaluator attached to such a project from the beginning would potentially lead to stronger outputs and may have helped us avoid some of the pitfalls we encountered in this project and were only able to unpack in hindsight. It is worth noting that almost all of the work of evaluating this project has been done on a voluntary basis.
- *Embrace complexity*: Viewing the project through a theoretical framework of complexity means that changing goals, plans and unpredictable outcomes are not seen as confounding variables but rather as an acknowledgement of the inevitable messy complexity that is the real world of long-term collaborative projects. As Greenhalgh and Papoutsi (2018) recommend that the focus should be on connecting different perspectives and systems by giving a voice to all the role players in a project, while acknowledging that there is no panacea to solving the challenges of a complex intervention introduced into a complex system.

While complexity in a project of this nature is inevitable, our experience and the wisdom of hindsight have highlighted the benefits of actively identifying and discussing aspects such as roles, expectations and assumptions throughout the life of a project. As is the case with any long-term qualitative project, the conclusions are often unexpected and the results which emerge, equivocal. A project of this nature is always going to be a long-term and dynamic undertaking. Ultimately, the various outcomes of this project were complicated and difficult to explain. An alliance between the aesthetic of performance and the methodological and theoretical ambitions of research was forged, although with some recasting needed. As

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Norris (2000) suggests there is value in reflecting on a project in its entirety in terms of inherent layers of complexity, from conception to production to outcomes.

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NOTES

1. https://throughpositiveeyes.org
2. https://bloodsugarsblog.wordpress.com/2018/03/25/blood-sugars-a-clip-from-the-performance/
3. https://en.wikipedia.org/wiki/FeesMustFall

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